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## Measuring the Quality of a Childhood Cancer Care Delivery System: Quality Indicator Development

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### ABSTRACT

**Objectives:** A set of indicators to assess the quality of a childhood cancer system has not been identified in any jurisdiction internationally, despite the movement toward increased accountability and provision of high-quality care with limited health care resources. This study was conducted to develop a set of quality indicators (QIs) of a childhood cancer control and health care delivery system in Ontario, Canada. **Methods:** A systematic review and targeted gray literature search were conducted to identify potential childhood cancer QIs. A series of investigator focus group sessions followed to review all QIs identified in the literature, and to generate a provisional QI set for a childhood cancer system. QIs were evaluated by three content experts in a sequential selection process on the basis of a series of criteria to select a subset for presentation to stakeholders. Following an appraisal of the relevance of quality assessment frameworks, remaining QIs were mapped onto the Cancer System Quality Index

framework. **Results:** The systematic review yielded few relevant childhood cancer system QIs. Overall, 120 provisional QIs were developed by the investigator group. Based on median QI rating scores, representation across the childhood cancer continuum, and feasibility of data collection, a subset of 33 QIs was selected for stakeholder consideration. **Conclusions:** The subset of 33 QIs developed on the basis of a systematic literature review and consensus provides the basis for the selection of a set of QIs for ongoing, standardized monitoring of various dimensions of quality in a childhood cancer system.

**Keywords:** health care, neoplasm, pediatric, quality appraisal, quality improvement, quality indicators, quality of care.

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### Introduction

Cancer remains the most common disease-related cause of death among children in North America [1–4], despite significant improvements in survival rates over the past 20 years [3,4]. Care for children with cancer is complex, due to the severity and high acuity of illness, intensity of care, and immediate and long-term consequences of treatment. Despite the existence of a set of quality indicators (QIs) of the cancer control system for adults in Ontario, Canada [5,6], and an increasing international interest in assessing the quality of pediatric cancer care using QIs [7], a set of indicators to assess the quality of a childhood cancer system has not been identified in any jurisdiction in Canada or internationally against which the overall system performance can be compared by using benchmarks.

A QI is defined as “a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality, and hence change in the quality, of care provided” [8]. QIs are being increasingly used to measure and improve the quality of health care and enable evidence-based

planning, management, and policy development [5,6,9]. The evaluation of outcomes, ability to measure key quality dimensions of the childhood cancer system, identification of potential gaps, and establishment of benchmarks for the practice of pediatric oncology are incrementally important domains of health care system evaluation and accountability in an era of providing high-quality care with limited health care resources in a publicly funded health care system.

The provincial coordination of childhood cancer services in Ontario, Canada, has been achieved through the Pediatric Oncology Group of Ontario (POGO), a collaboration of five specialty pediatric cancer programs within academic tertiary hospitals in Ontario and the community hospitals and cancer centers that deliver POGO provincial pediatric oncology programs. POGO identifies areas for cancer system development for the provincial Ministry of Health and Long-Term Care and operates in ongoing collaboration with families of children with cancer, survivors, corporate and private benefactors, and volunteers. As part of its mandate for advancing and monitoring the childhood cancer system, POGO has, since 1985, actively and prospectively

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collected standardized, population-based sociodemographic, diagnostic, therapeutic, and outcome data on each new case of childhood cancer diagnosed and treated in Ontario through its Networked Information System (POGONIS) [10]. POGO also oversees and funds the delivery of provincial pediatric oncology programs, including a pediatric oncology Satellite system of devolved care, operating at seven community-based hospitals; AfterCare—long term follow-up clinics for pediatric and adult survivors of childhood cancer; and Interlink—a nursing program that facilitates access to care and support services for children and their families at all stages of illness—in the hospital, community, and at home.

The aim of this study was to develop a quality assessment framework with a set of well-defined, evidence-based, and expert-informed QIs for the pediatric cancer system in Ontario, to be assessed by a multidisciplinary Delphi panel representing the broader provincial pediatric cancer stakeholder community.

## Methods

The development of a quality measurement set involved three phases: 1) review of quality assessment frameworks, 2) QI development and framework selection, and 3) assessing stakeholder agreement (modified Delphi process). We describe the first two phases in this article and phase three in a companion article [11].

### Phase I: Review of Quality Assessment Frameworks

A recent, comprehensive systematic review of quality assessment frameworks in the health, education, and social service sectors [12] was explored to assess the suitability of existing frameworks for a childhood cancer system. A total of 111 quality assessment frameworks were identified, none of which were specific to childhood cancer [12]. Based on a concept sorting exercise of 1488 quality domains, a set of 16 common quality concept areas was identified in the review (Table 1) [12] and used in this study to generate a provisional QI set.

### Phase II: QI Development and Framework Selection

#### Systematic review of existing QIs

Medline and Embase databases were searched for studies published between January 1, 1996, and April 30, 2010 (see Appendix A in Supplemental Materials found at <http://dx.doi.org/10.1016/j.jval.2013.03.1627>). English-language studies were included if one or more QIs for a pediatric cancer system were addressed. Studies were excluded if not available in full text, as were comments, editorials, letters, or conference papers/proceedings.

Citations were screened on the basis of title and abstract review for potential relevance to quality of care, quality improvement, quality assurance, benchmarks, standards of care, performance measures, or performance indicators and pediatric oncology. Citations that were related to both quality and childhood cancer were screened in full text by two reviewers, and all other citations were excluded.

A targeted scan of the gray literature (search strategy available from the authors upon request) was conducted in January 2009 (updated in April 2010) of 58 organizational and governmental Websites, including the Agency for Healthcare Research and Quality, and electronic databases of evidence-based quality measures [13] and guidelines [14] to identify existing pediatric cancer QIs. Generic adult cancer QIs in broadly applicable areas, such as symptom management, pathology reporting, and end-of-life care, were also searched from a number of measurement sets [6,15–17]. QIs were considered eligible for inclusion if they were pediatric cancer-specific QIs or concept areas. Those from the

**Table 1 – Sixteen common quality concept areas of health, education, and social service system quality assessment frameworks [12].**

Quality concept area	Definition
Access and Availability	<ul style="list-style-type: none"> <li>Extent to which services are available and accessible (geographic location, physical environment, affordability) in a timely manner.</li> </ul>
Coordination and Collaboration*	<ul style="list-style-type: none"> <li>Coordination: Provision of services that are continuous, integrated, and organized around the patient, both within and across service settings and over time.</li> <li>Collaboration: Linkages and partnerships that are established among different service delivery systems, networks, and providers to enable effective planning and the implementation of a high-quality integrated service.</li> </ul>
Equity and Fairness	<ul style="list-style-type: none"> <li>Provision of services that are of equal quality and that are distributed fairly across populations, regardless of patient characteristics (e.g., sex, ethnicity, impairment, geographic location, and socioeconomic status).</li> </ul>
Family-Centered†	<ul style="list-style-type: none"> <li>Extent to which the planning and delivery of services involves families, provides them with information to support their decision making, and is positive, acceptable, and responsive to their needs and expectations, and respectful of privacy, confidentiality, and differences (e.g., cultural, socioeconomic).</li> </ul>
Patient Safety	<ul style="list-style-type: none"> <li>Any actual or potential harm to the patient, through the provision of a service, that is prevented, avoided, reduced, or minimized through integrated risk management activities.</li> </ul>
Appropriateness	<ul style="list-style-type: none"> <li>Provision of services that are based on established standards and evidence and relevant to patient needs.</li> </ul>
Comprehensiveness	<ul style="list-style-type: none"> <li>Extent to which there is a range of services provided that is broad enough in scope and depth to meet patient needs.</li> </ul>
Workforce Development	<ul style="list-style-type: none"> <li>Degree to which a service delivery system manages and develops its workforce through a variety of processes (e.g., provision of a supportive and safe work environment, providing opportunities for learning and growth, and valuing staff satisfaction).</li> </ul>
Quality Improvement Processes	<ul style="list-style-type: none"> <li>System of processes and activities that promotes continuous quality improvement, including those related to program evaluation, performance monitoring, accountability, and accreditation.</li> </ul>

**Table 1 – continued**

Quality concept area	Definition
Creating and Using Knowledge	<ul style="list-style-type: none"> <li>• Extent of commitment to a continuous learning environment that supports research, the development, dissemination, and exchange of information and knowledge, and the creation and application of evidence-based practice guidelines and standards.</li> </ul>
Effectiveness	<ul style="list-style-type: none"> <li>• Extent to which a service achieves the desired result, assessed largely with reference to outcomes, which may be at the individual patient or broader population level.</li> </ul>
Patient/Family Perspective <sup>†</sup>	<ul style="list-style-type: none"> <li>• Extent to which the patient/family perspective and experience of a service is measured and valued as an outcome of service delivery.</li> </ul>
Leadership/Governance	<ul style="list-style-type: none"> <li>• How a service or organization engages in strategic planning processes to develop and facilitate the achievement of its values, mission, and vision, to be responsive to change, and to achieve sustainable success.</li> </ul>
Infrastructural Capacity	<ul style="list-style-type: none"> <li>• A service or organization infrastructure, e.g., physical facilities, equipment, fiscal resources, human resources, and information technology.</li> </ul>
Financial Management	<ul style="list-style-type: none"> <li>• Extent to which business and financial management plans are developed, implemented, and monitored, and address issues such as efficiency, resource allocation, stability, and process management.</li> </ul>

\*The original domains of “Collaboration” and “Coordination” were merged as “Collaboration and Coordination” because of overlap in quality indicators.

<sup>†</sup>The “Family-Centered” domain was adapted from “Client-Centeredness” in the original quality concept groups.

<sup>‡</sup>The “Patient/Family Perspective” domain was adapted from “Client perspective” in the original quality concept grouping.

gray literature were reviewed by two investigators to remove any duplicates.

#### Development of a provisional QI set

A series of investigator focus group sessions was held over 18 months to review all QIs identified from the literature and to generate a provisional QI set. The investigator group consisted of high-level decision makers from POGO, experienced pediatric cancer content expert clinicians, and methodologists in epidemiology, health services research, guidelines development, and performance measurement. The initial intent was to encompass the 16 common quality concept areas [12], which were used to brainstorm potential QIs of Ontario’s childhood cancer system.

Key considerations for the QI development were that indicators had to be comprehensive and span the childhood cancer care trajectory; have the potential to enhance or affirm the quality and level of functioning of the system; and have feasible data collection, including the identification of a probable source and the ability to retrieve and collect standardized data. The availability of known benchmarks and time frame for yielding new or actionable information were also considered. Provisional QIs were identified as being specific to Ontario or applicable to other jurisdictions and definitions were drafted.

#### Evaluation and selection of a subset of QIs

The provisional QIs were evaluated by three content experts to select a priority subset for presentation to stakeholders by using a modified Delphi panel process (described elsewhere) [11]. First, the experts undertook a “quick screen” review of each QI independently. QIs had to fulfill all four criteria of the quick screen phase, which assessed QIs on a categorical scale (“yes” or “no”) (Table 2). A second, independent scoring used seven selection criteria (Table 2) and a four-point Likert scale (where “1” = “strongly disagree” and “4” = “strongly agree”). This was completed for each QI that fulfilled all four quick screen criteria. An overall Likert score (maximum of 28) was calculated for each QI.

#### Further QI definition and specification

The priority QI subset was further refined to obtain a standardized measure with explicit predefined requirements for data collection and calculation of the measured value, including numerator/denominator specification, QI rationale, and source of data, risk adjustment or stratification, sampling time frame, and directionality and interpretation of the score.

#### Selection of a quality assessment framework for Ontario’s Childhood Cancer System

Although the 16 common quality concept areas [12] were useful for generating a comprehensive provisional QI list, other quality assessment frameworks were reassessed for applicability to Ontario’s childhood cancer system to select a feasible and understandable reporting structure.

## Results

### Phase I: Review of Quality Assessment Frameworks

None of the frameworks evaluated [12,18–20] were initially considered appropriate for assessing the quality of Ontario’s childhood cancer system. The 16 common quality concept areas [12], however, were held to provide the most comprehensive basis for generating QIs of this system.

### Phase II: QI Development and Framework Selection

#### Systematic review of existing QIs

The Medline and Embase search yielded 845 unique citations, of which 4 met the inclusion criteria [21–24] (Fig. 1) and are summarized in Table 3. None of the indicators proposed in these studies were adopted directly in the provisional QI set.

The National Institute for Health and Clinical Excellence’s 2005 Improving Outcomes in Cancer series [25,26] was the only source identified in the targeted gray literature search specific to childhood cancer. Its purpose was to give recommendations on service provision for children and young people with cancer based on the best available evidence, with links to 177 measurement suggestions ranging across 13 thematic concept areas

**Table 2 – Provisional quality indicator selection criteria.**

Selection criteria	Description
<b>Quick screen criteria</b>	
1. Overall importance	The QI measures an important health issue or aspect of the functioning of the childhood cancer system.
2. Relevance	This QI is relevant to capturing quality at the level of the system.
3. Alignment with childhood cancer mission statement	This QI aligns with the broadly applicable POGO childhood cancer mission statement.
4. Alignment with strategic objectives of the childhood cancer system	This QI aligns with at least one of eight broadly applicable POGO strategic objectives of the childhood cancer system.
<b>Primary selection criteria</b>	
1. Scientific soundness and face validity	This QI makes sense and measures what is intended and is reasonable to the larger community ( <i>face validity</i> ).
2. Relevance to quality improvement	This QI will drive quality improvement in childhood cancer care.
3. Relevance to health care accountability	This QI will increase health care accountability in childhood cancer.
4. Relevance to the identification of important system gaps	This QI will detect important gaps in childhood cancer care.
5. Directionality and interpretability	This QI demonstrates clear directionality and is interpretable, where changes in the indicator are commonly understood to be beneficial or negative.
6. Addresses a priority area	This QI measures a high-volume, high-risk, or high-needs issue in pediatric oncology.
7. Target audience	This QI will be meaningful and of interest to at least one target stakeholder group, including decision makers (e.g., MOHLTC and LHIN); hospitals (e.g., health care providers and hospital administrators); or families, parents, and/or survivors of childhood cancer.
LHIN, Local Health Integration Network; MOHLTC, Ministry of Health and Long-Term Care; POGO, Pediatric Oncology Group of Ontario; QI, quality indicator.	

spanning the childhood cancer continuum. The majority was concept constructs and not measurable QIs [25,26]. A number of the concept constructs were helpful in generating QIs (e.g., “number of pediatric intensive care admissions as a result of neutropenic sepsis,” “complication rates, particularly incidence of central venous line-associated infection”) [25,26]. Some were not applicable to the Canadian context (e.g., “demonstration of

adherence to the requirements of the European Union Directive on Good Clinical Practice”), while others were considered too microfocused (e.g., “access for patients who require dental follow-up posttreatment”), or were better suited for a research study (e.g., “effect of bereavement advice on quality of life of parents/carers and siblings”) [25,26].

#### *Development of a provisional QI set*

A total of 120 provisional QIs were generated, spanning the childhood cancer continuum and the 16 common quality concept areas [12]. Details of the 120 provisional QIs are available from the authors upon request. The most frequently measured quality concept area was Access and Availability, which encompassed 52 provisional QIs (43%).

#### *Evaluation and selection of a subset of QIs*

Based on the initial evaluation of provisional QIs, 89 (74%) met all four quick screen selection criteria (Fig. 2). These 89 QIs were scored highly, with 91% scored in the top quartile (median overall Likert score range of 14–28). Based on median overall Likert scores, representation across the childhood cancer care trajectory, and feasibility of data collection and implementation, a subset of 33 QIs was selected for presentation to stakeholders (Fig. 2). The majority were process indicators (70%), while six (18%) were structural indicators and four (12%) were outcome indicators. Some QIs were deemed better examined in research studies and excluded (e.g., health-related quality of life, cost-analysis of fever/neutropenia treatment in ambulatory vs. inpatient setting). Other QIs were excluded because of the lack of evidence for or consensus on a standard (e.g., acceptable wait time or delay in access to social work or neuropsychology).

#### *Further QI definition and specification*

Appendix B in Supplemental Materials found at <http://dx.doi.org/10.1016/j.jval.2013.03.1627> presents the subset of 33 proposed QIs, including the definition, source of data, rationale, and other technical specifications for the calculation of a measured value.

#### *Selection of a quality assessment framework for Ontario's Childhood Cancer System*

This QI subset was mapped onto the Cancer System Quality Index (CSQI) [18], which was considered to best reflect the key quality dimensions of the childhood cancer system and additionally, allow for comparability between provincial pediatric and adult cancer systems. The CSQI was developed by Cancer Care Ontario and the Cancer Quality Council of Ontario to monitor and report on Ontario's adult cancer system performance and includes seven quality dimensions [18], defined in Table 4. After the mapping exercise, all seven CSQI dimensions contained at least one proposed QI of the childhood cancer system (Table 5).

## **Discussion**

This study describes a process used to define and select a set of evidence- and consensus-based QIs for a childhood cancer system, leading to a prioritized subset of 33 QIs to be presented to stakeholders. The process used a systematic review, analysis of evidence, definition of key constructs of system quality and measurement specifications, and an iterative process for generating consensus. These 33 QIs span the childhood cancer continuum of care, from diagnosis and treatment to survivorship, and end-of-life care, and are quality measures of all seven dimensions of the CSQI. The set of 33 QIs is intended to reflect the perspectives of key stakeholder groups, including health care providers, survivors, families, policymakers, and decision makers.



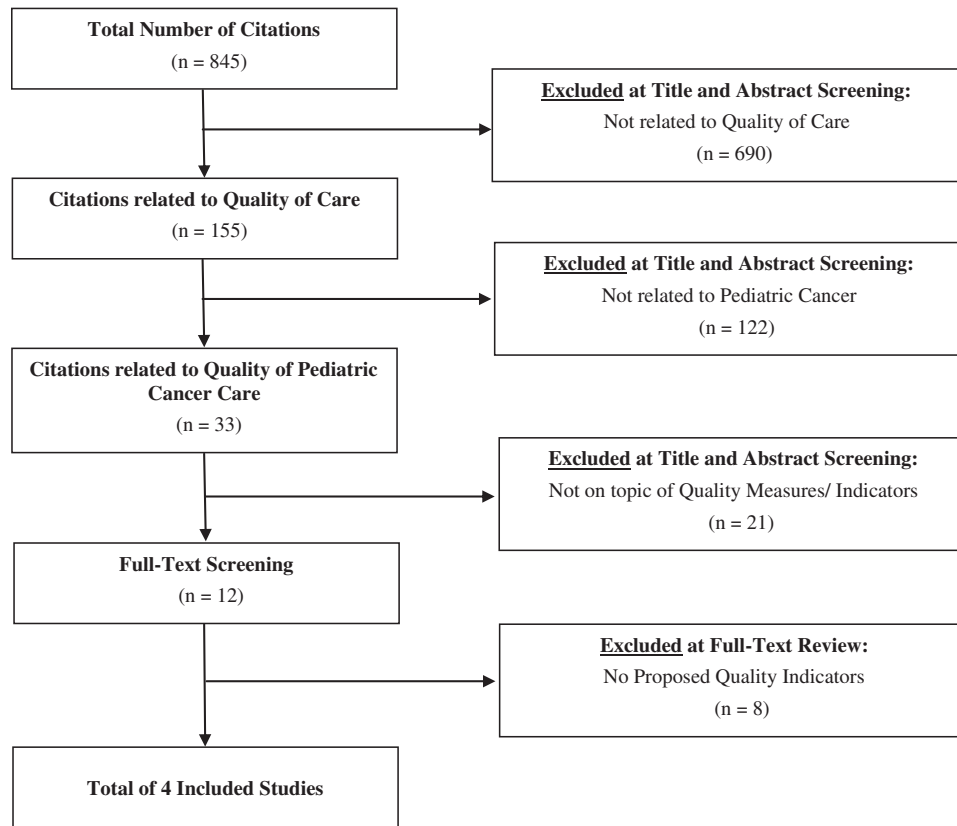


Fig. 1 – Search results.

Furthermore, this comprehensive indicator set will allow quality to be examined for various levels of care, including community-based and tertiary care, as well as for selected high-risk subpopulations, such as adolescents with cancer. Although the proposed QIs are focused on system quality in childhood cancer, both the processes used in defining and selecting a set of evidence- and consensus-based QIs within a quality assessment framework and some of the QIs, such as “Actual and Potential Drug and Dose Errors,” may be applicable to a broader range of pediatric disciplines and clinical practice and policy areas.

The QIs were evaluated on several selection criteria, including overall importance, relevance, alignment with a childhood cancer mission statement and strategic objectives, scientific soundness, interpretability, target audience, and priority area addressed. While the face validity of the provisional QIs was evaluated directly by content expert scoring, the content validity was also a key consideration of scientific soundness for a QI, which should accurately reflect the variable it has been intended to measure. While feasibility of data collection was considered in the development phase, it was used as a secondary selection criterion to capture highly important, relevant, and meaningful QIs for which data collection practices may not be established. Thus, in some instances, the data source was not limited to that currently collected in POGONIS, other existing registries, or administrative databases.

The proposed QI set includes measures of three fundamental dimensions of the care delivery system—structure, process, and outcome measures. Although outcome measures may not be measures only of system quality, these are appropriate for instances in which health care services have large effects on outcomes and data can be interpreted reliably, such as through

risk adjustment [27]. Furthermore, changes in survival rates are often used to evaluate the quality of care for cancer patients across different periods of time and jurisdictions [28].

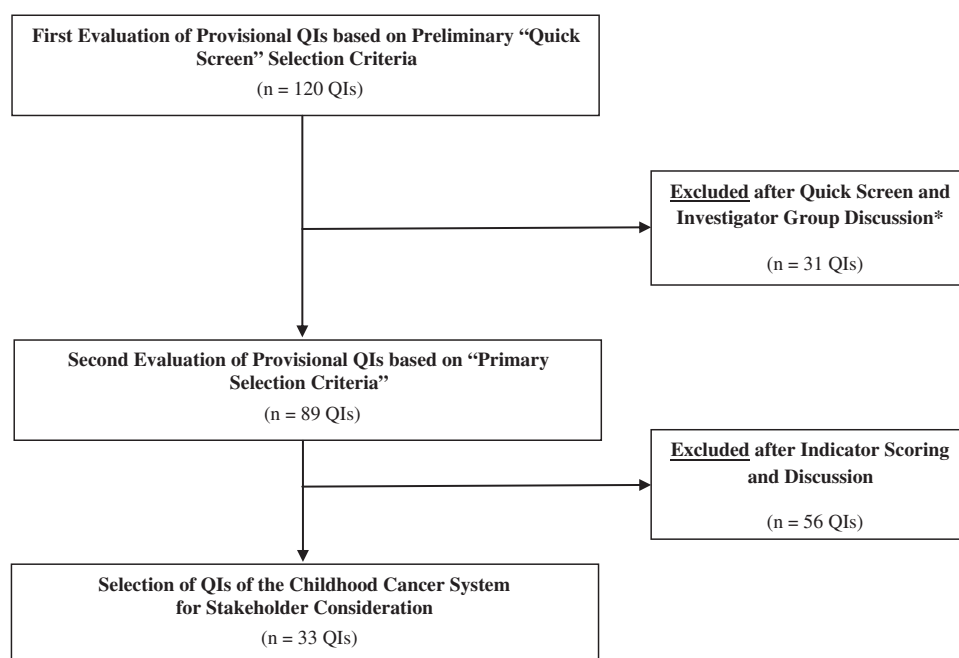
To date, no existing QI set has been developed for a childhood cancer system in any jurisdiction. For most areas of health services, quality-of-care assessment is evidence-based, yet limited evidence exists for quality measurement in pediatric oncology [7]. Some provisional QIs were excluded during the QI review phase because of challenges in the definition of a measurement that accurately reflects the content area being examined (content validity) and feasibility of data collection. Our set of prioritized QIs, however, has been defined with requirements for data collection and for the calculation of a standardized value, based on the best available evidence and expert consensus.

The majority of the 33 proposed QIs represent areas of system quality that could be applied to other jurisdictions. The proposed QI set, however, was developed to be applicable primarily to Ontario’s comprehensive childhood cancer system, and therefore, the five QIs pertaining to devolved pediatric oncology treatment, late effects surveillance, and a hospital, community, and home-based pediatric oncology nursing program (identified in Ontario as Satellite, AfterCare, and Interlink, respectively) may not be generalizable to other jurisdictions that have not established similar programs. Furthermore, although the construct of access and availability to ambulatory pediatric oncology drugs might be applicable to the quality of childhood cancer systems in other jurisdictions, the drug availability QI measure is particular to the Ontario Ministry of Health and Long-Term Care’s reimbursement process for specified drugs that require application through the Exceptional Access Program. Therefore, other jurisdictions should assess their local context to determine whether

**Table 3 – Summary of characteristics of included studies from systematic review.**

Study	Study objectives	Proposed QIs	Applicability to the provisional QI set
Dycus et al. [21]	To develop and test a Quality Improvement Knowledge, Skills and Attitudes (QuISKA) questionnaire to measure nursing quality knowledge, skills, and attitudes of practicing pediatric oncology nurses	<ul style="list-style-type: none"> <li>Nursing quality knowledge, skills, and attitudes (measured via the QuISKA questionnaire)</li> </ul>	Better examined in a focused research study and not as part of an ongoing systems-level performance measurement initiative
Pásztélyi et al. [22]	To report on “quality-of-care” indicators for new cases of five common groups of malignancies by the Hungarian Pediatric Oncology Working Group	<ul style="list-style-type: none"> <li>Length of stay in hospital due to treatment for initial disease;</li> <li>Diagnostic procedures, complications, or days in the ICU;</li> <li>Delays in treatment due to technical reasons or due to complications;</li> <li>Elapsed time from patient admission until first day of chemotherapy.</li> </ul>	Considered by investigator group; none directly adopted in provisional QI set
Oakes et al. [23]	To describe the development and implementation of an institutional quality improvement initiative to improve pain management for pediatric cancer inpatients at St. Jude’s Children’s Research Hospital in the United States	<ul style="list-style-type: none"> <li>Documentation of pain intensity by using numeric rating scales and</li> <li>Documentation of pain intensity at frequent intervals</li> </ul>	Patient-level symptom assessments and were not considered to be system-level QIs
Zernikow et al. [24]	National, longitudinal study (“STOP”) by the German Society of Pediatric Haematology and Oncology that aimed to <ul style="list-style-type: none"> <li>improve pediatric oncology pain control in Germany and</li> <li>evaluate the impact of the study on pain management quality</li> </ul>	<ul style="list-style-type: none"> <li>Number of pain assessments per day and per patient;</li> <li>Mean daily pain rating;</li> <li>Percentage of daily pain rating &gt; 3 using a 1 to 6 smiley scale (where 1 = “no pain” and 6 = “most pain”)</li> </ul>	Patient-level symptom assessments and were not considered to be system-level QIs

ICU, intensive care unit; QI, Quality indicator.

**Fig. 2 – Results of provisional quality indicator evaluation by content experts. QI, quality indicator. \*Thirty-one indicators were excluded on the basis of the quick screen evaluation and discussion among the three content experts.**

**TABLE 4 – Seven quality dimensions of the Cancer System Quality Index (CSQI) [18].**

Quality dimension	Quality dimension definition
Safe	Avoiding, preventing, and ameliorating adverse outcomes or injuries caused by health care management.
Effective	Providing services based on scientific knowledge to all who could benefit.
Responsive	Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.
Integrated	Coordinating health services across the various functions, activities, and operating units of a system.
Accessible	Making health services available in the most suitable setting in a reasonable time and distance.
Equitable	Providing care and ensuring health status does not vary in quality because of personal characteristics (sex, ethnicity, geographic location, and socioeconomic status).
Efficient	Optimally using resources to achieve desired outcomes.

**Table 5 – Proposed quality indicators of Ontario's Childhood Cancer System (n = 33), by Cancer System Quality Index (CSQI) quality dimension.**

Safety (n = 6)		Effectiveness (n = 7)	
<ul style="list-style-type: none"> <li>• Chemotherapy certification of nursing staff</li> <li>• ICU Admissions due to neutropenic sepsis</li> <li>• Potential drug/dose errors</li> <li>• Actual drug/dose errors</li> <li>• Central venous line infection rate</li> <li>• Major clinical trial protocol violation</li> </ul>		<ul style="list-style-type: none"> <li>• Five-year overall relative survival</li> <li>• Five-year event-free survival</li> <li>• Treatment-related mortality</li> <li>• Use of conformal or intensity-modulated RT</li> <li>• Access to PET scanning</li> <li>• Supportive care guidelines</li> <li>• Guidelines for nutritional support</li> </ul>	
Integration (n = 6)		Responsiveness (n = 1)	
<ul style="list-style-type: none"> <li>• Eligible patients enrolled in Satellite for chemotherapy*</li> <li>• Shuttle sheet</li> <li>• Eligible survivors enrolled in AfterCare*</li> <li>• Survivors with a survivor care plan<sup>†</sup></li> <li>• Patients referred for end-of-life Interlink care*</li> <li>• Case coordinator</li> </ul>		<ul style="list-style-type: none"> <li>• Parent/guardian satisfaction</li> </ul>	
Accessibility (n = 8)		Equity (n = 4)	
<ul style="list-style-type: none"> <li>• Clinical trial participation</li> <li>• First therapeutic intervention wait time</li> <li>• Chemotherapy admission delay</li> <li>• After hours cancer surgery</li> <li>• Wait time: Sedation for ambulatory procedures</li> <li>• Adolescent cancer diagnosis in a pediatric center<sup>‡</sup></li> <li>• Sufficient multidisciplinary staff</li> <li>• Access to expert management of pain control</li> </ul>		<ul style="list-style-type: none"> <li>• Adolescent cancer diagnosis in a pediatric center<sup>‡</sup></li> <li>• Eligible patients enrolled in Satellite for chemotherapy*</li> <li>• Eligible survivors enrolled in AfterCare*</li> <li>• Patients referred for end-of-life Interlink care*</li> </ul>	
		Efficiency (n = 10)	
		<ul style="list-style-type: none"> <li>• Drug availability</li> <li>• Time taken for the production of pathology reports</li> <li>• Adolescent cancer diagnosis in a pediatric center<sup>‡</sup></li> <li>• Eligible patients enrolled in Satellite for chemotherapy*</li> <li>• Eligible survivors enrolled in AfterCare*</li> <li>• Survivors with a survivor care plan<sup>†</sup></li> <li>• Patients referred for end-of-life Interlink care*</li> <li>• End-of-life care days spent in acute care</li> <li>• Interdisciplinary team meetings</li> <li>• Tumor boards</li> </ul>	

ICU, intensive care unit; PET, positron emission tomography; RT, radiation therapy.

\*This indicator is assigned to the Integration, Equity, and Efficiency quality dimensions.

<sup>†</sup>This indicator is assigned to the Integration and Efficiency quality dimensions.

<sup>‡</sup>This indicator is assigned to the Accessibility, Equity, and Efficiency quality dimensions.

the QIs are applicable to their health care systems and may wish to revise QIs or measure a subset of applicable QIs.

In the future, consideration may need to be given to additional areas of a childhood cancer system, such as the quality of transition of care for adolescents on active cancer treatment into adulthood, or the quality of therapies offered when a cooperative group clinical trial protocol is not available. Furthermore, QI sets should be periodically reassessed and QIs potentially modified, removed, or

added to maintain relevance to the status of the current health care system.

## Conclusions

The 33 QIs provide the basis for a set of indicators for ongoing, standardized monitoring of various quality dimensions of a

childhood cancer system. The acceptability of these QIs among key stakeholders of the system should be tested to determine their validity, acceptability, importance, and meaningfulness. Once implemented, these indicators can provide evidence based on comparable and standardized measures of system quality that can be used to stimulate and optimize accountability and continuous improvement within the health care system.

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## Supplemental Material

Supplemental material accompanying this article can be found in the online version as a hyperlink at <http://dx.doi.org/10.1016/j.jval.2013.03.1627> or, if a hard copy of article, at [www.valueinhealthjournal.com/issues](http://www.valueinhealthjournal.com/issues) (select volume, issue, and article).

## REFERENCES

- Public Health Agency of Canada. Cancer in children in Canada (0-14 years). Available from: <http://www.phac-aspc.gc.ca/cd-mc/cancer/fs-fi/cancer-child-enfant/index-eng.php>. [Accessed February 16, 2012].
- Public Health Agency of Canada. Leading causes of death and hospitalization in Canada. Available from: <http://www.phac-aspc.gc.ca/publicat/lcd-pcd97/table1-eng.php>. [Accessed February 16, 2012].
- Canadian Cancer Society/National Cancer Institute of Canada. Canadian Cancer Statistics 2008. Toronto, Canada: Canadian Cancer Society, 2008.
- Ries LAG, Smith MA, Gurney JG., et al. Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975-1995, National Cancer Institute, SEER Program (NIH Pub. No. 99-4649). Bethesda, MD: National Cancer Institute, 1999.
- Greenberg A, Angus H, Sullivan T, Brown AD. Development of a set of strategy-based system-level cancer care performance indicators in Ontario, Canada. *Int J Qual Health Care* 2005;17:107-14.
- Cancer Quality Council of Ontario. Cancer System Quality Index (CSQI). Available from: <http://www.csqi.on.ca/>. [Accessed April 18, 2011].
- Knops RR, Hulscher ME, Hermens RP, et al. High-quality care for all children with cancer. *Ann Oncol* 2012;23:1906-11.
- Campbell SM, Braspenning J, Hutchinson A, Marshall M. Research methods used in developing and applying quality indicators in primary care. *Qual Saf Health Care* 2002;11:358-64.
- Canadian Partnership against Cancer. The 2011 Cancer System Performance Report. Available from: <http://www.partnershipagaincancer.ca/wp-content/uploads/2011-Cancer-System-Performance-Report.pdf>. [Accessed February 16, 2012].
- Greenberg ML, Barr RD, DiMonte B, et al. Childhood cancer registries in Ontario, Canada: lessons learned from a comparison of two registries. *Int J Cancer* 2003;105:88-91.
- Bradley NME, Robinson PD, Greenberg ML, et al. Measuring the quality of a childhood cancer care delivery system: assessing stakeholder agreement. *Value Health* 2013;16:639-46.
- Klassen A, Miller A, Anderson N, et al. Performance measurement and improvement frameworks in health, education and social services systems: a systematic review. *Int J Qual Health Care* 2010;22:44-69.
- Agency for Healthcare Research and Quality. National Quality Measures Clearinghouse (NQMC). Available from: <http://qualitymeasures.ahrq.gov/>. [Accessed May 1, 2010].
- Agency for Healthcare Research and Quality. National Guideline Clearinghouse (NGC). Available from: <http://guideline.gov/>. [Accessed May 1, 2010].
- American Society of Clinical Oncology. Quality oncology practice initiative. Available from: <http://qopi.asco.org/Methodology>. [Accessed May 1, 2010].
- National Cancer Institute. Cancer quality of care measures project, 2008. Available from: <http://outcomes.cancer.gov/areas/qoc/canqual/phase2.html>. [Accessed May 1, 2010].
- American Society for Radiation Oncology (ASTRO), American Society for Clinical Oncology (ASCO), American Medical Association (AMA). Physician consortium for performance improvement oncology measures. Available from: <http://www.ama-assn.org/ama/pub/physician-resources/physician-consortium-performance-improvement/pcpi-measures.page>. [Accessed May 1, 2010].
- Cancer Quality Council of Ontario. Cancer System Quality Index (CSQI): quality dimensions. Available from: [http://www.csqi.on.ca/quality\\_dimensions/](http://www.csqi.on.ca/quality_dimensions/). [Accessed April 18, 2011].
- Kaplan RS, Norton DP. The balanced scorecard – measures that drive performance. *Har Bus Rev* 1992;70:71-9.
- Hospital Report Research Collaborative, Government of Ontario, Ontario Hospital Association, Canadian Institute for Health Information (CIHI). Hospital Report 2007: Acute Care. Ottawa, Canada: Canadian Institute for Health Information, 2007.
- Dycus P, McKeon L. Using QSEN to measure quality and safety knowledge, skills, and attitudes of experienced pediatric oncology nurses: an international study. *Qual Manag Health Care* 2009;18:202-8.
- Pásztélyi Z, Schuler DC, Czvenits E. Practice guidelines in pediatric hematopathology: implementation and survey. A possible way for medical quality assurance. *Pediatr Hematol Oncol* 2000;17:679-85.
- Oakes LL, Anghelescu DL, Windsor KB, Barnhill PD. An institutional quality improvement initiative for pain management for pediatric cancer inpatients. *J Pain Symptom Manage* 2008;35:656-69.
- Zernikow B, Hasan C, Hechler T, et al. Stop the pain! A nation-wide quality improvement programme in paediatric oncology pain control. *Eur J Pain* 2008;12:819-33.
- National Institute for Health and Clinical Excellence/National Collaborating Centre for Cancer. Guidelines on Cancer Services: Improving Outcomes in Children and Young People with Cancer: The Manual. London, United Kingdom: National Institute for Health and Clinical Excellence, 2005.
- National Institute for Health and Clinical Excellence/National Collaborating Centre for Cancer. Guidelines on Cancer Services: Improving Outcomes in Children and Young People with Cancer: The Evidence Review. London, United Kingdom: National Institute for Health and Clinical Excellence, 2005.
- Mant J. Process versus outcome indicators in the assessment of quality of health care. *Int J Qual Health Care* 2001;13:475-80.
- Dama E, Pastore G, Maule MM, et al. Avoided deaths as an indicator of improvement of childhood cancer treatment. *Eur J Cancer Prev* 2007;16:453-9.